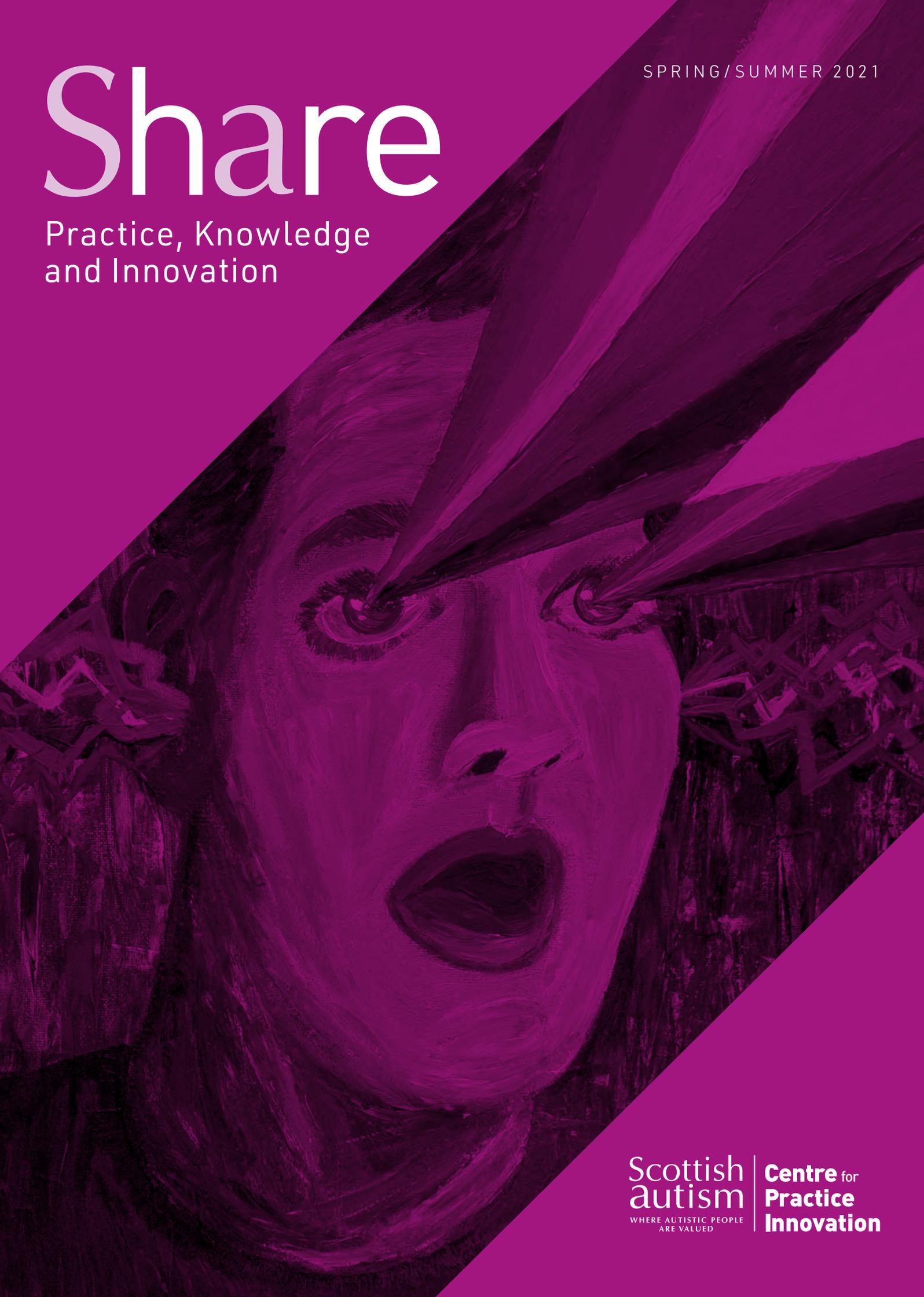


SPRING/SUMMER 2021

Share

Practice, Knowledge
and Innovation



Scottish
autism
WHERE AUTISTIC PEOPLE
ARE VALUED

**Centre for
Practice
Innovation**

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Cover photo: Senses of the Overload by Sean Baxter who was part of the Winter Connections Online Art Group. You can view Sean's original artwork and the rest of the gallery at www.scottishautism.org

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From the Editor



Dr Joe Long
Research and Policy Lead,
Scottish Autism

Welcome to Issue 13 of Share. I write in May 2021 as things start to open up again and we come out of lockdown for the second, or in some cases, third time. As we do so most of us working in public services or the third sector, are determined that things cannot go back to how they were before the pandemic. Autistic people deserve better. Making that change can only happen by listening and responding to the experiences of autistic people. The articles in this issue document important aspects of autistic experience to recognise, and ways in which we can create forums and spaces for the expression of lived experience.

In recent years, research literature on autism has included an increased focus on 'masking' or 'camouflaging' – in which autistic people feel that they have to change their natural communication style, or embodied identity in order to 'fit in' in a non-autistic world. In her overview of autistic masking, Amy Pearson describes this phenomenon as a response to stigma, and sounds a timely note of caution that autistic diversity means that we should not assume that autistic people are masking if they do not fit stereotypes.

Creating inclusive spaces, where autistic people don't feel they have to mask, and where diverse thinking and communication styles are not only accepted but embraced and valued should be an aspiration to all of us. The *Flow Unlocked* creative

project is one such space, described here by Georgia Pavlopoulou, Briony Campbell and Jon Adams, a longtime friend to Scottish Autism who has shared his insights and creative work with us on many occasions. The project shows what can happen when knowledge about autistic experience is produced by and with autistic people, rather than about them.

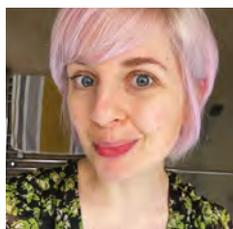
Rachel Birch's article on initiating an autistic employee forum at Scottish Autism outlines the benefits of such a forum not just for those colleagues who participate – in finding community, and a safe space to share experiences – but for the whole organisation as empowered forum members share their experiences and suggest ways in which the organisation might improve its inclusion practices for autistic staff.

The theme of finding positive experiences in an employment context is continued here in our conversation with Alex Dafalla, who shares what it has meant to him to have a job in his local community of Perth.

All of us need to think carefully about how we make our workplaces, research practices and community events more inclusive and empowering. Listening to autistic voices and responding to the lived experience that we hear articulated must always be our first step.

Autistic Masking

What do we need to know?



Dr Amy Pearson
Senior Lecturer in
Psychology,
University of Sunderland

Masking in autistic people (also called camouflaging by researchers) is increasingly gaining attention, but it is something that autistic people had been talking about in community discussions for years before it reached the consciousness of Psychologists. It is defined as the suppression of parts of your identity in order to avoid negative judgements or 'blend in' in non-autistic spaces. This may be conscious (like forcing yourself to make eye contact even if it is uncomfortable) or unconscious (learning over time to automatically minimise the amount you talk about a favourite topic, to the point where you don't have to think about doing so).

In a recent article published in the journal *Autism in Adulthood*, Kieran Rose and I discuss what we know about masking so far, and what has been missing from academic discussions. Since around 2016, Psychologists have become more interested in the concept of masking. They have examined what kinds of things people explicitly label as masking (like making eye contact, being aware of your tone of voice, etc), and the places that autistic people report feeling the need to mask (like work, with friends, etc). However, there has been a lack of research into why masking occurs, and how it develops.

To understand why autistic people mask, we have to take a look at the social world that autistic people live in. Since the development of autism as a diagnostic category, ideas about what autism is have been incredibly negative. Psychological research in particular has labelled autism as characterised by a set of 'deficits' across a range of different areas, including how we communicate, attention, and imagination. While autistic people might have a different set of

strengths and challenges to the non-autistic population, communicate in different ways, and need more or less support with daily living, there is not a 'wrong' way to be human. However, this deficit narrative has led to autism being seen as a tragedy, where autistic people are seen as less than human. Negative judgements about a person based on aspects of their identity is called stigma. The experience of stigma can be very harmful and is often associated with bullying and abuse, all of which lead to poor outcomes for mental health, physical health, and suicidality. This should make it unsurprising that autistic people might learn to mask, in order to try to avoid stigma and bullying.

“ The experience of stigma can be very harmful and is often associated with bullying and abuse, all of which lead to poor outcomes for mental health, physical health, and suicidality. ”

Another issue is that we don't know very much about autistic social identity outside of masking research and how autistic people view themselves in relation to other people in their social groups. Classic social psychology theory suggests that all people modify how they appear at least a little bit when interacting with different people (for example, you might not speak to your boss in the same way that you might speak to your best friend). We don't really know whether autistic people use these same social strategies, or how they monitor how they appear in different social situations. More research into autistic social strategies are needed to understand the key differences between masking, and other forms of social self-monitoring (i.e. masking might mean hiding your 'true self', whereas social self-monitoring might mean just being a little bit more formal in certain situations).

There have also been a lot of arguments about the relationship between masking and gender. Some

“ Autistic people don’t fit one particular stereotype, look like one particular type of person, and (unsurprisingly, given that they are human) are as diverse as any other group of people. ”

researchers suggest that women are ‘better’ at masking, and this is why they might be missed, or mis-diagnosed compared to men. We argue that this point of view shifts responsibility away from practitioners learning about how to move away from stereotypes of autistic people, and instead almost blames autistic people who don’t fit the stereotype with being ‘hard to spot’. Autistic people don’t fit one particular stereotype, look like one particular type of person, and (unsurprisingly, given that they are human) are as diverse as any other group of people. Autism doesn’t have a particular race, or gender, yet we know that women, non-binary people and people who are Black or from other minority ethnic groups are diagnosed at a lower rate than men. We argue that it is important to understand what masking can include, but that it is also important that we do not suggest that an autistic person who does not fit a stereotype (i.e. is interested in Korean Pop music instead of trains) is ‘hiding’ their autism under ‘seemingly normal’ interests. It is by no means easy to untangle masking and ideas around what autism ‘looks like’, but we suggest that clinicians would benefit from continued professional development in innovative autism research, and training which involves autistic people.

“ We need to look at how masking develops across the lifespan, and how we can support people in feeling safe enough to be themselves. ”

There are a lot of exciting potential areas for investigation in relation to masking that can improve the lives of autistic people. We need to look at how masking develops across the lifespan, and how we can support people in feeling safe enough to be themselves. We can also look at whether things like difficulty identifying your own emotions (alexithymia) can make it difficult to notice the stress that comes from masking long term, and how this relates to experiences of burnout. We also need to understand the relationship between masking and other aspects of a person’s identity (i.e. their gender, race/ethnicity, sexuality) as many people experience stigma in multiple ways. We cannot reduce a person’s identity down to one factor (i.e. being autistic) as our identities are made up of many components, and experiences of masking and its consequences (both positive and negative) are likely to differ across people. Further research into these areas will help us to better understand masking, and what we can do to mitigate some of the impact.

Exploring autistic people's relationships before and during the pandemic



Georgia Pavlopoulou
Psychologist,
Autism Researcher &
Neurodiversity Advocate,
University College London



Jon Adams
Neurodivergent Artist,
Polymath, Synaesthete
& Mental Health Champion



Briony Campbell
Artist, Facilitator
& Project Manager

Autistic people face unique challenges and opportunities to socially connect to others, and to form relationships within their communities. Those who do enjoy these connections are happier, physically healthier and live longer, with fewer mental health problems than people who are less well connected. Focused on communities in East London, *Flow Unlocked* is a collaborative knowledge exchange project, which highlights the importance of relationships to autistic people's mental health and quality of life.

Autistic relationships are rich, nuanced and creative and have proved to be a wonderful theme for a dynamic creative collaboration aiming to raise awareness of the social determinants of autistic mental health. The intense sensitivity with which autistic people relate to the world is rarely recognised, let alone celebrated. This is why our *Flow Unlocked* group has been reflecting on the breadth of personal and sensory relationships that have sustained them before and during the pandemic, as well as those they have missed. These reflections are revealed through poetry, photography, drawing and film.

Who we are

We are a collaborative; Georgia Pavlopoulou, is a psychologist, autism researcher & neurodiversity advocate - founder of University College London's Group for Research in Relationships in NeuroDiversity; Jon Adams is a neurodivergent artist, polymath, synaesthete and mental health champion; Briony Campbell is an artist, facilitator and project manager.

If we were allowed to define our professional environments by our mindsets rather than our jobs, we would tell you that ours are closely aligned. We share a belief in the importance of human relationships for good mental and physical health and we share a dream of a society which not only makes space for, but also offers equal opportunity to, it's diverse range of participants.

The Project Objectives

Our objectives, as co-established with our autistic consultants group during a four month period of collaborative work include:

- To support autistic East Londoners to co-create artistic reflections of their relationships under lockdown. (Relationships with people, places, animals, sensory stimulus).
- To explore the relationships between autistic people and their neurotypical allies, by looking at those within our project.
- To address the questions of authenticity and representation pertinent to creative collaboration with participants from marginalised groups.
- To share our processes, insights and outcomes in order to expand the conversations beyond our *Flow Unlocked* group.
- To refine, evaluate and record our distinct 'iterations' methodology, so it can be used by other participatory practitioners, particularly those working with marginalised groups.

Flow Unlocked: The story behind the name

Briony brought up the idea of Regents Canal and Lee River as a geographical focal point for the project,

seeing it as a metaphorical flowing artery of her ever-changing neighbourhood, which both connects and divides us. Georgia found an inspiring connection to the positive psychological theory of 'flow state'. The theory of flow state is popular among autistic thinkers as it resonates with the ability of autistic people to have extended focus, and to hyper-focus on areas of interest. This optimal experience can help autistic people to maintain a positive view of self and the world. We are interested in how the flow of autistic people's relationships is interrupted or enhanced during lockdown, due to new rules and changes of routines. This idea of flow versus lockdown is echoed in the geography of East London's waterways, with their weirs and locks designed to control flow, travel and ultimately connection. The canals also provide a plethora of visual stimulations with their inherent combination of natural and constructed elements.

This project has gifted me the opportunity and encouragement to express, through a creative and open peer-led safe space, my hurts and hopes for the relationships I struggle to maintain during Covid-19. When projects involve autistic people in genuine participation, we create safe spaces where creativity, friendship and authenticity can flow.

Jon Adams, Artist

In developing this idea the project ran a series of creative workshops with autistic people to stimulate discussions around autistic relationships, mental health, loneliness, connection, sound, space, pattern and flow. In response to our autistic consultant's feedback we explored creative representations of their relationships with people, places and sensations. We went beyond the conventions of traditional psychological work which historically focusses on autistic brain differences, often missing the qualitative descriptors of relationships that contribute to wellbeing. Collaboratively we devised a multi-disciplinary creative framework following an experience-sensitive approach to consider autistic adults' sense of place, authenticity,



The Imposter's Syndrome, Jon Adams



Making Sense of the Strangeness. Briony Campbell

agency, personal journeys and meaning-making. This experience-sensitive approach offered participants a unique and respectful experience.

I find Georgia's attitude to academic research refreshing, as she puts the needs of the people she studies before her need to study. A participatory art methodology is a natural fit for her activist approach to studying autism. In return I offer my understanding of the intense process of documenting one's own intimate relationships through a creative process, and navigating the high and lows it can provoke.

Briony Campbell, Artist

Finally, we have started to create art which will raise awareness of the autistic experience. Too often in academia there is a power imbalance within collaborations - a researcher decides a topic, conducts research about autistic people rather than with them, or artists are instructed to respond to researcher's pre-existing ideas). In contrast, the conversations that have led up to this exhibition have been dynamic, mutually inspirational and authentically collaborative. We hope that our poetry, visual art and films can highlight in beautiful ways, issues around the government's pandemic response, and the consequent opportunities and challenges faced by autistic people and their vital relationships within East London.

Flow Unlocked has seen a dynamic re-formulation of roles for the sharing of power and knowledge. Redefining narratives around autism from the perspective of lived experience is vital to building an inclusive community.

To see the art work created within the project visit: <https://flowunlocked.co.uk/> and follow [#FlowUnlocked](#) on Twitter

Flow Unlocked was funded by University College London's UCL Culture fund.

The Benefits of an Autistic Employee Forum



Rachel Birch
Services Manager,
Scottish Autism

Scottish Autism has gone through a number of transformations over the years, as our understanding of autism and the needs of autistic people in Scotland has developed. If you've ever been on our website's About Us section you will have seen that we were "Established in 1968 by a group of parents". Today we are a diverse organisation made up of around 1000 employees from a wide variety of backgrounds. Some are still parents or family members of autistic people, and this experience and passion is as valued today as it was in 1968. Most importantly, we also have autistic employees like myself.

You will find autistic people in roles within Scottish Autism across the organisation from direct support staff to practice development advisors, and leadership positions. Our focus on improving the lives of all autistic people in Scotland naturally made some autistic people want to work with us, and to stay once they were in the door, as it did in my case. However, our employment practices have historically been driven by what is considered good HR practice in the wider sector, rather than specifically asking ourselves how we could be an employer of choice for autistic people.

In early 2019 I delivered a workshop at our staff conference entitled *Autism and Employment: Reflecting on our own Management and Recruitment Practices*. A number of projects have come out of this, one of which was the creation of our Autistic Employee Forum. Long before the existence of that forum, I knew how life changing peer support could be, from my own experiences with friends as well as those I've had with a number of peer support organisations. In those spaces and with those people, I would continually find myself wishing I had access to something similar, but with

people who knew what it was like to be autistic whilst working in my profession.

When I first started working with Scottish Autism I knew of only two other openly autistic colleagues in the whole organisation. My experience today is very different. In the past few months, the Autistic Employee Forum has become what I had felt a need for whilst engaging in other peer and professional support spaces.

I've experienced the forum as a place where I've been able to explore whether my experiences as an employee were shared by others who were also autistic. These experiences have been ones which, despite having a positive working relationship with my own managers and colleagues, I had never shared. Ultimately, what had been the barrier to me sharing many things, was shame due to self and societally imposed stigmas. Our society piles such stigmas onto autistic people at an alarming rate from the very earliest years of childhood. They can be absolutely paralysing and rip the voice right out of us. Discovering my experiences were shared by other autistic employees whom I respected took all of that out the equation; now it wasn't *me*, it was *our* experience. It also gave me an added motivation to approach those topics with my line manager by highlighting the fact I could potentially help other autistic employees by doing so. This was of particular importance since some are not widely recognised autistic needs in employment.

" I've experienced the forum as a place where I've been able explore whether my experiences as an employee were shared by others who were also autistic. "

Even as an autistic person myself, I never stop learning about what good autism practice is - whether that be through learning from others, discussions within the autistic community, my experiences as a practitioner and leader, or even self-reflecting and using myself as

my own research subject (big bonus of being an autistic autism professional!). Yes, I am autistic and have all the added insight which that brings, but I know for certain there have been times where I could have improved in my own management and leadership of other autistic employees. My experience with the Autistic Employee Forum has not only helped me as an employee, but also made me a better manager and leader for my own autistic employees.

“ Thanks to a senior leadership team who let me crack on with such an initiative with more support and trust than I could have asked for, I have experienced an enormous culture change in a very short period of time. ”

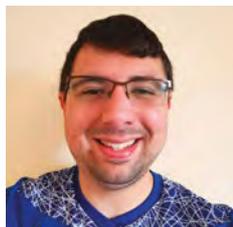
I hope that as the forum grows and embeds itself as a core platform for autistic employee engagement, that more and more examples of good practice are shared from there for the benefit of non-autistic colleagues and line managers. Thanks to a senior leadership team who let me crack on with such an initiative with more support and trust than I could have asked for, I have experienced an enormous culture change in a very short period of time. I now receive fortnightly organisation-wide staff e-zines which have recently included communications from autistic employees in each issue. Those communications so far have come in the form of: videos; writing; and even regular songs written and performed by an autistic colleague as a way of communicating their lived experience. One piece of writing was called “Dear Questioner”, which an autistic colleague wrote for others who may be questioning whether they are autistic. The piece shares how the forum has helped them, being, in their words, “life-changing”, providing reassuring answers to the stressful questions they had ruminating in their mind.

I sit here now finishing this article after attending an online social gathering of the autistic employee forum. This evening’s gathering was the first time I’d had a chance to speak at length with one of the newer employees to join us. They kindly shared tonight that what made them want to work for Scottish Autism most was “seeing someone in such a senior role within the organisation be openly autistic”. I also shared with them how nice it is for me now not to be the only openly autistic employee in my service area, and to have a culture where people can be more openly and authentically themselves in work, which seems to have been beneficial for all.

“ This culture change has resulted in me feeling happier and more able to be my authentic self in work than I have ever been in my life. ”

This culture change has resulted in me feeling happier and more able to be my authentic self in work than I have ever been in my life. In a sector where recruitment and retention can be so challenging, and lived experience can add so much value, that is something worth sharing.

My job, and what it means to me



Alex Dafalla

Alex contacted Scottish Autism earlier this year, keen to share his experiences of finding and sustaining work. Here he answers questions from Joe Long, editor of Share magazine.

Alex, tell us a little bit about your job and what you enjoy most about it.

Alex: I am a Team Member at Greggs Perth. I have worked there since October 2013. My shop provides takeaway and sitting in. My shop can be very busy as it is based in a city centre. On a morning shift I set up the store which means arranging all the freshly prepared stock for the day to be ready for shop opening. The part I enjoy the most is serving the customers tasty food. I have regular customers that will come in for a small chat when they are placing and receiving their order. I enjoy working as part of a

“ I have regular customers that will come in for a small chat when they are placing and receiving their order. I enjoy working as part of a team where I can help and chat with my colleagues. ”

team where I can help and chat with my colleagues.

Joe: How did you find your job, did you have support in looking for work?

Alex: I used an online job search engine called Indeed and found the job being advertised in Perth. I filled out the application all by myself. I was contacted by Greggs and they invited me to an interview. After the interview, Greggs contacted me again and they said I was successful and offered me the job. I was over the moon and was very much looking forward to starting work. The Perth One Stop Shop helped me by speaking to Greggs on my behalf to have systems in place for me to help me in the workplace, for example I have a set work pattern.

Joe: What does it mean to you to have a job?

Alex: My job is an important part of my life because it gives me structure to my day, it gives me valuable independence skills, allows me to socialise with my colleagues and customers, and makes me feel happy to help people in the community. The job

“ The job gives me a sense of responsibility in the community and I feel I am a valued employee. ”

gives me a sense of responsibility in the community and I feel I am a valued employee of Greggs.

Joe: What has your employer done to support you in maintaining your job?

Alex: I have been able to maintain my job through many different ways. My current manager is very understanding of my needs for me to be able to do my job. I work 16 hours a week and I work set days and shifts. This helps to give structure to my week and stops me from becoming too overwhelmed and stressed. I need a lot of prompting and reminders while doing tasks in the workplace. There are guides in place around the shop that help me with this. My manager reminds me of what Greggs is

expecting from all employees.

Joe: What advice would you give to employers wanting to better support autistic employees?

Alex: For employers to have understanding and awareness and to work with the individual to have strategies in place at work that help them to do the job.

Joe: You told us that you have been furloughed for several months, what has that been like and what are you most looking forward to when you return to work?

Alex: I did find things difficult at first when I could not work for a long period of time, I struggled with not having a routine in place, interaction with colleagues and customers. After a while I changed my attitude on life and started engaging with activities online, such as Magic the Gathering online tournaments and discussions, online fitness classes with Scotland All Strong and virtual drop in with Number 3 [The Perth One Stop Shop for autistic people]. I went out for a walk or a run each day as this is important for my mental and physical wellbeing.

I also tried something new by getting into building and painting Warhammer models. I found this very relaxing and helped to fill in my time. I have connected with my local Warhammer shop in Perth and have received really good help and advice for me to get started in the hobby.

I am looking forward to getting back to work for a sense of normality, having structure to my week and interacting with customers and colleagues.

Joe: As well as your job, what interests and activities help you to maintain your wellbeing?

Alex: I am a big football fan and I support my local

team, St Johnstone. Before the pandemic, I used to go along to the football matches at McDiarmid Park on a Saturday afternoon. I enjoy being amongst

“ I used to go along to the football matches at McDiarmid Park on a Saturday afternoon. I enjoy being amongst my fellow Saints fans watching my team play and do well. ”

my fellow Saints fans watching my team play and do well.

I started playing in a Pub Pool League where I competed against local pubs in Perth on a Thursday evening. This gave me a sense of enjoyment and opportunity to interact with new people, which helps my wellbeing. I enjoy going on my bike around my local area and exploring new cycle routes.

Joe: Thank you so much for sharing your experiences with us, Alex. We wish you luck on your return to work!

NEWS AND EVENTS



#OurVoiceOurRights

Time to make rights a reality for autistic people and people with a learning disability.

Campaign for a Commissioner secures cross-party support

Our Voice Our Rights is a campaign that urged the main political parties in Scotland to commit in the May 2021 Scottish Parliamentary Elections to the world's first Commissioner for autistic people and people with a learning disability. Together with partners ENABLE Scotland and the National Autistic Society Scotland we are delighted to have secured cross-party support for the Commissioner. There is still much work to be done, but a very positive step forward for much needed change. Find out more at www.ourvoiceourrights.org

Scottish Autism Research Group Seminar

The Scottish Autism Research Group, a cross institutional group for autism researchers based in Scotland will hold a two-day seminar on **23rd and 24th August 2021**.

Find out more at <https://www.sarg.ed.ac.uk/home/>

Participatory Autism Collective: Critical Autism Studies Conference 2021

The Participatory Autism Research Collective (PARC) in partnership with the Critical Autism and Disabilities Studies Research Group at London South Bank University will be running a free one-day online conference on **7th June 2021 9am-2pm (BST)**.

Find out more on the PARC website:

<https://participatoryautismresearch.wordpress.com/>

Save the Date: Scottish Autism Conference

The Scottish Autism Conference, themed 'Behind the Mask' and originally was scheduled to be held in Autumn 2020 has been rescheduled to **May 2022**.

Visit www.scottishautismconference.org and follow Scottish Autism on social media for details.



National Post Diagnostic Support Service Event

This service will provide a wide range of information and support to autistic people of all ages as well as their parents and families following diagnosis. Funded by the Scottish Government, the National Post Diagnostic Support Service will ensure families are better informed and empowered. It will also support autistic individuals to understand and embrace their identity whilst giving them and their families the opportunity to connect with peers.

An event on **Thursday 3rd June at 10am** will give participants further insight into the support available within the service. We will be joined by our partner organisations National Autistic Society Scotland, Autism Initiatives Scotland, Autistic Mutual Aid Society Edinburgh (AMASE), Autism Rights Group Highland (ARGH), Triple A's and the Scottish Women's Autism Network (SWAN). We will share information about the support and services that are available. There will also be an opportunity to ask questions.

Learn more at <http://bit.ly/NPDSevent>

The Centre for Practice Innovation provides a focus for practitioners, researchers and organisations to come together and collaborate, share knowledge and ideas and shape innovative autism practice.

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Practice
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WHERE AUTISTIC PEOPLE
ARE VALUED

Contact us.

Centre for Practice Innovation
100 Smithfield Loan
Alloa
FK10 1NP

Tel: **01259 720 044**

Email: **CPI@scottishautism.org**

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